



Latest release

Future Aboriginal and Torres Strait Islander Health Surveys - Have Your Say

Discussion paper for Aboriginal and Torres Strait Islander people to give feedback on the proposed Aboriginal and Torres Strait Islander health survey

Reference period 2020

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Overview

The Australian Bureau of Statistics acknowledges the traditional custodians of country throughout Australia and recognises their continuing connection to land, waters and community. We pay our respects to them and their cultures, and Elders, both past and present.

The ABS is committed to early and ongoing conversations with Aboriginal and Torres Strait Islander people to help shape an upcoming health survey. This paper provides information about the upcoming survey and seeks your feedback on a range of topics.

You may also be interested in attending an interactive online workshop or completing an online self-paced consultation package, talking with an engagement manager, or completing our online survey. For further details, see [How Can I Have My Say?](#)

The ABS would like to thank all who have given their voice to the consultation process to date. Their knowledge and experiences have provided invaluable insights, and their contributions are forming part of an essential dialogue towards a greater understanding of Aboriginal and Torres Strait Islander peoples' data needs.

Introduction

In August 2019, the Commonwealth Minister for Health announced a new national Intergenerational Health and Mental Health Study (IHMHS). The Study will run over three years from late 2020 to 2023 and comprise surveys of health,

nutrition and physical activity, and an optional biomedical survey (see Appendix 1: Overview of the IHMHS). There will also be a [National Survey of Mental Health and Wellbeing](#), which was last conducted in 2007. As was the case for the [Australian Health Survey](#) (AHS) in 2011-2013, the ABS' Aboriginal and Torres Strait Islander survey program will be expanded under the IHMHS to accommodate the collection of this information across the Aboriginal and Torres Strait Islander population, from 2022 to 2023.

The ABS is committed to early and ongoing conversations with Aboriginal and Torres Strait Islander peoples to ensure all surveys are done in a culturally appropriate way and reflect the priorities, values and diversity of Aboriginal and Torres Strait Islander peoples. Discussions with several Aboriginal Community Controlled Health Organisations (ACCHOs) have occurred, alongside the considerable advice and guidance provided to ABS by their national body (NACCHO). Their advice is influencing our approach to engagement with Aboriginal and Torres Strait Islander communities, including in developing the content of this paper. The ABS Round Table on Aboriginal and Torres Strait Islander Statistics (consisting of Aboriginal and Torres Strait Islander peoples from across the country) has also provided invaluable feedback and direction for how we should undertake this focussed engagement.

The mental health survey component of the IHMHS is a total population survey which does not have an Aboriginal and Torres Strait Islander specific component, although the topic of mental health is part of the ABS' engagement for the Aboriginal and Torres Strait Islander Health Survey. This is discussed further in the survey content section of this paper.

Now we need to hear from you to help us shape the Aboriginal and Torres Strait Islander survey components which will be undertaken as part of the IHMHS. We want to hear about your information needs and how the data should be collected to help make the survey culturally appropriate and successful and we're seeking input on three broad issues:

1. Survey content
2. Biomedical tests
3. Data integration

This discussion paper provides one avenue for consultation and should be considered as the beginning of a conversation rather than the conclusion.

How can I have my say?

The ABS is committed to providing a range of opportunities for Aboriginal and Torres Strait Islander people to provide feedback and we are asking you to tell us your thoughts and suggestions on all elements of the proposed health survey including how and what information should be collected.

There are many ways you can provide your feedback to us:

Attend an online workshop

Between September and November 2020, the ABS will be running a series of online workshops. The online workshops are interactive and provide an opportunity for you to share your feedback and ideas on three broad topics:

- Health survey content
- Biomedical testing
- Data integration

For more information or to register please visit [ETM Perspectives](#), or contact us at coeatsis@abs.gov.au.

Online self-paced consultation package

For people who aren't able to attend a workshop, an online self-paced consultation package is available. For more information or to register please visit [ETM Perspectives](#), or contact us at coeatsis@abs.gov.au.

Connect with an engagement manager

The ABS has Aboriginal and Torres Strait Islander [Engagement Managers](#) in each state and territory who are keen to have discussions with you.

Complete our eSurvey

The electronic survey covers a range of key topics and discussion points as well as the ability to provide general comments. For those interested, the survey can be accessed here [ABS Consultation Hub](#)

Write to us

In addition to, or instead of, attending an online workshop or completing an online self-paced consultation package, the ABS invites people to submit written feedback in response to this discussion paper.

Submissions are welcome until 31 March 2021 and can be forwarded electronically or in hard copy using the contact details below.

Email: coeatsis@abs.gov.au

Or by post to:

Director of CoEATSIS

Locked Bag 10

Belconnen ACT 2616

A report on the engagement undertaken will be made available at the end of the consultation.

Health related survey content

The Aboriginal and Torres Strait Islander components of the IHMHS are expected to start collecting information from participants in mid-2022. The proposed components include:

- National Aboriginal and Torres Strait Islander Health Survey (NATSIHS) – a general health survey which collects information about health conditions, risk factors and health behaviours
- National Aboriginal and Torres Strait Islander Nutrition and Physical Activity Survey (NATSINPAS) – a survey which collects detailed information about dietary intake and physical activity.

Both of these surveys will include an option to volunteer for biomedical testing.

We expect the first release of data will be in December 2023.

As a health focused study, the majority of questions in the IHMHS will be about health topics. However, as in previous health surveys it will include some social topics such as language, culture, education and employment, which provides for regular national reporting (including Closing the Gap reporting) on these topics.

The topics included in previous Aboriginal and Torres Strait Islander health surveys are listed in Appendix 2. There may also be scope to expand on the social content that would usually be collected in an ABS health survey. Topics included in previous Aboriginal and Torres Strait Islander social surveys are listed in Appendix 3. Detailed data item lists and questionnaires from previous health and social surveys can be accessed via Appendix 4.

Collection of mental health related information

The IHMHS includes the National Survey of Mental Health and Wellbeing which uses a diagnostic tool for the assessment of mental disorders known as the Composite International Diagnostic Interview (CIDI). The survey was designed to provide prevalence estimates of selected lifetime mental disorders at the national level, and was last conducted in 2007.

The ABS recognises the importance of having current data about mental health conditions experienced by Aboriginal and Torres Strait Islander peoples. To collect this, the CIDI needs testing, and likely modification, to make it both culturally appropriate and able to adequately capture relevant social and cultural determinants of mental health for Aboriginal and Torres Strait Islander peoples. The existing CIDI is a thorough assessment tool which can place a significant burden on participants, and it has not been tested with Aboriginal and Torres Strait Islander people living in remote areas.

Equally important is that the data collection process is modified to accommodate a flexible approach and ensure there are adequate support structures incorporated for Aboriginal and Torres Strait Islander people when responding to a mental health survey. For these reasons, the IHMHS does not have an Aboriginal and Torres Strait Islander specific mental health prevalence survey. The ABS will continue to working closely with the Department of Health, the National Indigenous Australian's Agency and other stakeholders to plan for future collection of Aboriginal and Torres Strait Islander mental health data, informed by further research.

It should also be noted that while mental health was not the sole and specific focus of the most recent [National Aboriginal and Torres Strait Islander Health Survey](#) (2018-19), it included various data items relating to mental health and wellbeing, including:

- Whether ever been diagnosed with a mental health condition
- Type of diagnosed mental health condition
- Whether has psychological disability
- Accessed/used health services for mental health condition
- Whether been to a counselling service in the last 12 months
- Reason(s) didn't go to counsellor in the last 12 months
- Whether consulted a psychologist in the last 2 weeks
- Social and emotional wellbeing

The subject of mental health is part of the engagement we are currently undertaking for the broader IHMHS.

In your response to this paper, the ABS is seeking your input on:

- The key emerging health (including mental health) issues facing Aboriginal and Torres Strait Islander people today.
- What are your priority data needs, including what is currently not available?
- What information should or shouldn't be collected? (The topics listed in Appendices 2 and 3 may be used as a guide).

Biomedical testing

Voluntary biomedical testing will be included in the National Health Measures component of the IHMHS. Biomedical testing involves taking small samples of blood, urine or saliva to test for things like diabetes, cholesterol levels, kidney disease, and nutrient levels such as iron, folate and Vitamins B12 and D. All samples will be disposed of at the end of the survey by the pathology company undertaking the testing, but participants may be able to choose to have their samples stored under secure and culturally appropriate governance arrangements for additional testing and research. Participants will be provided with the information to ensure they know what they are consenting to and what tests will be undertaken.

Biomedical testing was part of the 2012-13 AHS' NATSIHS and NATSINPAS survey components and was undertaken with ethics approvals from numerous ethics committees. Results from the tests were returned to the participant and with consent, to their doctor and/or medical clinic. Those with high risk levels, along with their clinician, were contacted directly by the pathologist to initiate necessary care. The collection in 2012-13 was only undertaken with adults in an attempt to build trust with the Aboriginal and Torres Strait Islander community before potentially extending the opportunity to children. The possible inclusion of children for the upcoming biomedical collection is part of the conversation we are seeking to have with Aboriginal and Torres Strait Islander communities.

The tests conducted in the 2012-13 NATSIHS* included:

Topic	Tests
Cardiovascular Disease	Cholesterol, Triglyceride, HDL, LDL, Apolipoprotein B
Diabetes	Fasting Plasma Glucose, HbA1c
Kidney Disease	Albumin, eGFR, Creatinine
Liver Function	ALT, GGT
Smoking	Cotinine
Nutrition	Folate, B12, Sodium, Potassium, Vitamin D, Iodine, Iron
Other	C-reactive protein (CRP)

* See Appendix 5 for details.

Biomedical testing has several benefits including:

- Improving the health status of people by informing decisions made across the health sector
- Providing insights into the relationship between biomedical results, behavioural risk factors and rates of chronic disease
- Helping develop and improve preventative health assessment measures for chronic diseases, e.g. diabetes, cardiovascular disease, kidney disease.
- Contributing to changes in health policy and clinical practice

In addition to the biomedical tests and potential storage of samples, the ABS is also seeking input on whether to consider including an option for genomic testing on stored samples, subject to stringent ethical and governance requirements. In some of our discussions to date, support has been voiced from Aboriginal and Torres Strait Islander peoples that they be offered the opportunity to be involved in genetic research as they can see there are potential benefits for their community. In 2011, at a Lowitja Institute Roundtable on genetic research, Professor Emma Kowal noted, "Genetic research can provide insight into why some people from the same family respond differently to treatments; why some people are resistant to disease and others susceptible to the same disease, even when they might live in identical environments; and can provide clues about how diseases develop." Kowal E, and Anderson I. Genetic Research in Aboriginal and Torres Strait Islander Communities: Continuing the Conversation, The Lowitja Institute, 2012

We acknowledge there are some concerns around the potential misuse of genomic testing due in part to historical misrepresentation and the feeling across the community that genomic testing has never worked in favour of Aboriginal and Torres Strait Islander peoples. As part of the consent process for people choosing to participate in the biomedical collection, the ABS will need to clearly communicate how the samples will be used, stored, accessed and disposed. To inform this we are seeking your input to help us understand how to respectfully incorporate Aboriginal and Torres Strait Islander peoples' cultural beliefs into the communication and consent process.

In your response to this paper, the ABS is seeking your input on the following biomedical test items:

1. How important is it for Aboriginal and Torres Strait Islander people to participate in a voluntary biomedical collection and what barriers are there to their participation?
2. What do you think are the potential benefits and/or risks to Aboriginal and Torres Strait Islander people from analysis of biomedical tests data?
3. What ethics, consent and/or governance processes are needed for a biomedical collection to occur in a culturally appropriate way?
4. Sensitivities people are likely to have with the collection of biomedical samples
5. What tests should be included? Why?

6. Should children be included in the collection of samples?
7. Should sample storage under appropriate governance, be considered to allow for future tests?
8. Should consent for sample storage allow an option for genomic testing, under appropriate governance?

Data integration

Data integration brings together information from multiple sources to help answer important questions about people, families, places, businesses or life events. Combining health survey results with Census and administrative government data can help provide a better picture of the health of Aboriginal and Torres Strait Islander peoples.

Linked (or integrated) data that is used for analysis in data integration projects is de-identified, meaning it does not contain identifying information like names and addresses. Other important measures are taken to ensure the data is not likely to identify an individual and all information is protected under the [Census and Statistics Act](#).

- Data integration has a range of benefits including:
- Better understanding of people's lived experiences
- Improved information for planning services for the future
- More local level data
- Better use of existing data, and replacing some data collected in surveys, to help reduce the burden of surveys on participants.

More information about data integration can be found on the ABS website at www.abs.gov.au/dataintegration.

The Multi-Agency Data Integration Project (MADIP)

One way the ABS currently integrates data is through the Multi-Agency Data Integration Project (MADIP). MADIP is a secure approach for combining information from across areas of government like healthcare, education, government payments, personal income tax, Census and other population demographic data over time.

Current MADIP data sources

Apprenticeships *	Early Childhood Development *	Census *	Medical Practitioners	Census *
Australian Apprenticeships Incentives Program and Training Contracts	Australian Early Development Census	Census of Population and Housing	Centralised Register of Medical Practitioners	Australian Census Longitudinal Dataset
Deaths *	Medical Services	Medicare	Health *	Higher Education *
Death Registrations	Medicare Benefits Scheme (MBS)	Medicare Enrolments Database (MEDB)	National Health Survey (NHS)	Higher Education Information Management System (HEIMS)
Medication Use	Tax	Welfare *	Migration	Disability, Ageing, and Carers *
Pharmaceutical Benefits Scheme (PBS)	Personal Income Tax (PIT)	Social Security and Related Information (SSRI)	Migrant Data	Survey of Disability, Ageing, and Carers

* Includes Indigenous status

The ABS is one of six Australian Government agencies that work together to manage MADIP. The MADIP allows authorised researchers to better understand socio-economic outcomes and trends to help inform policy, services and programs to make sure they are valuable to the people and communities who need them. Information from MADIP cannot be used for compliance purposes, like checking if you are paying enough tax, or whether you are eligible for government payments.

More information about MADIP can be found on the ABS website at www.abs.gov.au/madip.

Privacy and security

The ABS takes [data security](#) very seriously and prioritises protecting our respondents' privacy. We fully comply with the [Privacy Act 1988](#), the Australian Privacy Principles and all other relevant legislation.

Data is only integrated where there is a clear public benefit and can only be used for statistical and research purposes. The ABS enables integration of the datasets that are part of MADIP, but these datasets are not held together. They are stored separately and information from them is only brought together for specific approved projects and the ABS uses a secure environment for access and storage. Authorised researchers are only granted access to anonymous information, and only the information they need for their project. The ABS checks data outputs before they are shared. The ABS does not release information in a manner likely to enable the identification of an individual.

Access to MADIP data is only available to authorised users. Before anyone can access integrated data, the project must be approved by all relevant data custodians and the ABS. All projects must meet the requirements of the 'Five Safes Framework' which is in line with international best practice and designed to identify and manage any risks to keep the information safe and secure.

The Five Safes Framework covers separate but related dimensions:

- Safe people: Is the researcher authorised to access and use the data appropriately?
- Safe projects: Is the data to be used for an appropriate purpose?
- Safe settings: Does the access environment prevent unauthorised use?
- Safe data: Has appropriate and sufficient protection been applied to the data?
- Safe output: Are the statistical results non-disclosive?

Opportunity to integrate Health Survey and administrative data

In December 2019, the first results from the [2018-19 NATSIHS](#) were released. There is a lot of interest from researchers about combining NATSIHS data with government administrative data, such as through MADIP. Currently, no NATSIHS or National Aboriginal and Torres Strait Islander Social Survey (NATSISS) data are used in any data integration project.

The NATSIHS cannot collect everything about peoples' health, or associated social and economic circumstances. It also represents one point in time, which means there can be limitations in using it to assess outcomes and impact, and telling stories about peoples' life journeys. Integrating NATSIHS data would mean more information is available with the survey data, which would allow researchers to see more complete pictures of people's health and wellbeing. For example, a topic that could be explored is whether use of medical services and medications follows the best care pathways (eg. using Medicare and PBS data). Data integration could also enable more complex analysis and open up more possibilities for local level data. We would also be in a better position to explore what information can and can't be gained from administrative data to reduce the burden of future surveys, reduce survey length, or create space in surveys for the data that communities need.

In your response to this paper, the ABS is seeking your input on the following data integration items:

- What are your thoughts about integrating NATSIHS and future surveys with MADIP?
- What integrated information would be most useful for you or your organisation?
- What data governance arrangement is needed to manage access to integrated NATSIHS data?
- What topics would be important to research?
- Could data integration help with other data gaps that you are aware of?
- What is needed to make integrated data accessible?
- Are there any particular risks you are concerned about in keeping data safe?

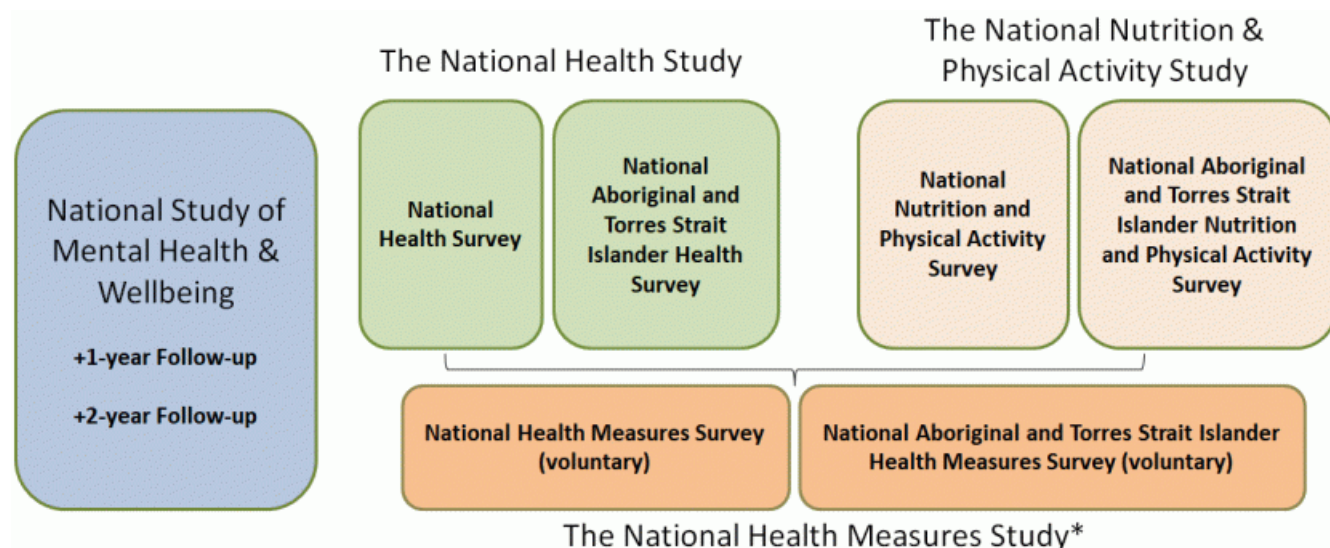
Appendix 1 - Overview of the IHMHS

[Show all](#)

Image

Description

The Intergenerational Health and Mental Health Study (IHMHS)



* Includes voluntary biomedical component

Appendix 2 - Topics included in previous Aboriginal and Torres Strait Islander health surveys

[Show all](#)

Health status and conditions

Topic	Collected in 2012-13	Collected in 2018-19
Self-assessed health	Yes	Yes
Social and emotional well-being	Yes	Yes
Disability	Yes	Yes
Asthma	Yes	Yes
Arthritis	Yes	Yes
Cancer	Yes	Yes
Cardiovascular	Yes	Yes
Diabetes	Yes	Yes
Sight	Yes	Yes
Hearing	Yes	Yes
Kidney disease	Yes	Yes
Osteoporosis	Yes	Yes
Mental Health conditions	N/A	Yes
Other long-term conditions	Yes	Yes
Medications	N/A	Yes
Recent injuries	Yes	N/A
Time away from study and work	Yes	N/A

Health related actions

Topic	Collected in 2012-13	Collected in 2018-19
Breastfeeding	Yes	Yes
Contraception	Yes	N/A
Hospital visits	Yes	Yes
Private health insurance	Yes	Yes
Usual and preferred healthcare provider	Yes	Yes
Doctor consultations	Yes	Yes
Oral health	Yes	Yes
Other health professionals	Yes	Yes

Physical measures

Topic	Collected in 2012-13	Collected in 2018-19
Blood pressure	Yes	Yes
Physical measures	Yes	Yes
Body mass	Yes	Yes
Hearing test	N/A	Yes

Health risk factors

Topic	Collected in 2012-13	Collected in 2018-19
Alcohol	Yes	Yes
Smoker status	Yes	Yes
Tobacco consumption	Yes	Yes
Substance use	Yes	Yes
Immunisation	Yes	Yes

Nutrition and physical activity

Topic	Collected in 2012-13	Collected in 2018-19
Diet - general	Yes	Yes
Diet – 24-hour food recall	Yes	N/A
Physical activity - general	Yes	Yes
Physical activity – measured pedometer data	Yes	N/A

Social

Topic	Collected in 2012-13	Collected in 2018-19
Language	Yes	Yes
Educational attainment*	Yes	Yes
Current study	Yes	Yes
Employment*	Yes	Yes
Income	Yes	Yes
Cultural identification	Yes	Yes
Family stressors	Yes	N/A
Discrimination	Yes	Yes
Removal from natural family	Yes	Yes
Experiences of violence	N/A	Yes
Personal pensions and allowances	Yes	Yes

* The health survey is a data source for Closing the Gap targets on these topics.

Appendix 3 - Topics included in previous Aboriginal and Torres Strait Islander social surveys

[Show all](#)

Language and culture

Topic	Collected in 2008	Collected in 2014-15
Speaking/learning Australian Indigenous language	Yes	Yes
Cultural identification	Yes	Yes
Cultural participation	Yes	Yes
Cultural education	Yes	Yes

Social contact and community strength

Topic	Collected in 2008	Collected in 2014-15
Social contact	Yes	Yes
Social networks	Yes	Yes
Social support	Yes	Yes
Sense of efficacy	Yes	Yes
Level of trust	Yes	Yes
Perceptions of community leadership and change	N/A	Yes
Child sports	Yes	Yes
Child positive life events	Yes	Yes
Child care	Yes	Yes

Housing, mobility and transport

Topic	Collected in 2008	Collected in 2014-15
Homelessness	N/A	Yes
Housing utilisation and overcrowding	Yes	Yes
Household facilities, maintenance and structural problems	Yes	Yes
Housing tenure	Yes	Yes
Housing mobility	Yes	Yes
Access to transport	N/A	Yes
Transport use	Yes	Yes
Possession of a driver's licence	Yes	Yes
Community facilities available	Yes	Yes

Stressors, safety, law and justice

Topic	Collected in 2008	Collected in 2014-15
Personal and family stressors	Yes	Yes
Barriers to service providers	Yes	Yes
Unfair treatment	Yes	Yes
Bullying and unfair treatment at school	Yes	Yes
Removal from natural family	Yes	Yes
Feelings of safety	Yes	Yes
Contact with the justice system	Yes	Yes
Experiences of violence	Yes	Yes

Health

Topic	Collected in 2008	Collected in 2014-15
Self-assessed health	Yes	Yes
Social and emotional well-being	Yes	Yes
Long-term health conditions	N/A	Yes
Disability status	Yes	Yes
Infant and maternal health	Yes	Yes
Breastfeeding	Yes	Yes
Child health and nutrition	Yes	Yes
Child sleep	Yes	Yes
Adult nutrition	N/A	Yes
Smoker status	Yes	Yes
Alcohol	Yes	Yes
Substance use	Yes	Yes
Patient experience	N/A	Yes

Education, employment and income

Topic	Collected in 2008	Collected in 2014-15
Educational attainment*	Yes	Yes
Current study	Yes	Yes
Vocational training	Yes	Yes
Child education	Yes	Yes
Employment*	Yes	Yes
Difficulties finding work	Yes	Yes
Income	Yes	Yes
Personal pensions and allowances	Yes	Yes
Financial stress	Yes	Yes

* The social survey is a data source for Closing the Gap targets on these topics.

Appendix 4 - Data item lists and questionnaires from previous health and social surveys

Show all

Detailed data item lists and questionnaires can be downloaded from the ABS website. Further information about survey content and comparability over time can be found in the accompanying survey explanatory material and user guides – links provided below.

Health surveys

[2018-19 National Aboriginal and Torres Strait Islander Health Survey – data item list and questionnaire](#)

[2018-19 National Aboriginal and Torres Strait Islander Health Survey – explanatory material](#)

[2012-13 Australian Aboriginal and Torres Strait Islander Health Survey – data item list and questionnaire](#)

[2012-13 Australian Aboriginal and Torres Strait Islander Health Survey – Users' Guide](#)

Social surveys

[2014-15 National Aboriginal and Torres Strait Islander Social Survey – data item list and questionnaire](#)

[2014-15 National Aboriginal and Torres Strait Islander Social Survey – explanatory material](#)

[2014-15 National Aboriginal and Torres Strait Islander Social Survey – Users' Guide](#)

[2008 National Aboriginal and Torres Strait Islander Social Survey – data item list and questionnaire](#)

[2008 National Aboriginal and Torres Strait Islander Social Survey – Users' Guide](#)

Appendix 5 - Biomedical tests in the 2012-13 NATSIHS

Show all

Cardiovascular disease

Biomarker	Rationale
Total cholesterol	To estimate prevalence of cardiovascular disease risk factors
Fasting triglycerides	
Fasting LDL and HDL cholesterol	
Apolipoprotein B	

Diabetes

Biomarker	Rationale
Fasting plasma glucose	To estimate prevalence of diabetes and impaired fasting glucose
Glycated haemoglobin HbA1c	To monitor diabetes control

Chronic kidney disease

Biomarker	Rationale
Estimated Glomerular Filtration Rate (eGFR)	To estimate prevalence and severity of kidney damage
Urinary albumin creatinine ratio (ACR)	To estimate prevalence of albuminuria, an early indicator of kidney damage

Liver function

Biomarker	Rationale
Liver function tests (GGT and ALT)	To provide an indication of prevalence of liver damage

Risk factors

Biomarker	Rationale
Serum cotinine	To estimate prevalence of active and passive smoking

Nutrition status

Biomarker	Rationale
Erythrocyte folate	To monitor the effectiveness of folate food fortification programs and estimate prevalence of folate deficiency
Serum folate	
Serum B12	To estimate prevalence of vitamin B12 deficiency
Urinary sodium and potassium concentration	To measure population trends in sodium and potassium intakes
Serum 25(OH)D	To estimate prevalence of vitamin D deficiency
Urinary iodine	To monitor the effectiveness of iodine food fortification programs and estimate prevalence of iodine deficiency
Serum ferritin	To estimate prevalence and severity of iron deficiency
Serum transferrin receptor	
Haemoglobin	
Inflammation marker (CRP)	To assist with iron interpretations

History of changes

Show all

30/11/2020 - Extended cut off date for written feedback from 30 November 2020 to 31 March 2021

16/09/2020 - New details on online workshops and self-paced consultation package has been added

Previous catalogue number

This release previously used catalogue number 4740.0